



Illness as Many Narratives

Arts, Medicine and Culture

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Illness as Many Narratives

Πονόμετρο δε βρίσκεται για να μετρά τον πόνο
τον πόνο τον κατέχουνε όσοι τον έχουν μόνο.

There is no instrument to measure pain
it can only be measured by those who experience it.

(Cretan *mantináda*)

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Illness as Many Narratives

This book starts from the premise that illness narratives are characterised by multiplicity. Among the texts and artworks I encountered in my research, few have driven this idea home (in all its different senses) to me more than my father's own cancer narrative. His untitled story is unfinished and remains unpublished, handwritten in a language that would not be accessible to an Anglophone audience without translation. Reading it a couple of years after his death in 2009, as two kinds of readers inhabiting the same body – a daughter and an academic equipped with various critical tools – I found myself being moved and intellectually intrigued by several of its features.

My father was trained as a mathematician, acquiring expertise in what I considered to be the ultimate discipline of abstraction, and never hid his admiration for numbers. Yet, with the exception of one mathematical equation he devises to explore the relationship between finite life and the concept of infinity (often treated as if it were a number in mathematics), the tools he uses to endow his experiences with meaning are narrative tools. This is not to say that his is a straightforward or single narrative. In its multiplicity of styles, it refuses easy categorisation: one can find diary sections with medical facts and details, but these are integrated into a larger life narrative, and the latter, in turn, into what has been described in literary studies as 'narrative of community'.¹ My father's story was, consciously or not, documenting not only the everyday rituals of illness and a body in crisis but also details of the rich local life of a Cretan village, where he grew up: the lives of its few remaining inhabitants (improvised stories that emerge, as his narrative indicates, as these people pass by the porch where he sat to write on their way to their daily business), small and large events, traditions under threat by a range of social and cultural changes in Greece; in short, a collective story with the ability to 're-enchant' his illness narrative by investing in other stories and encounters outside

of the clinical framework of patients and doctors.² These narratives, personal and collective, are often interrupted by interpolated drawings (of his garden and the view of the sky's horizon from where he sat to write), signalling the need to turn to a visual medium to communicate aspects of his story better, as well as by what is known as *mantináda* (μαντινάδα in Greek), an oral tradition associated with poetry, music and performance.³ Especially prominent on the island of Crete, *mantináda* refers to a compressed narrative or short poem that typically consists of rhyming couplets. It is often improvised and recited in the rhythm of accompanying music at feasts and other singing events. When composed and performed in this way, a verse elicits a response by another person and this in turn leads to another response – the dialogue continues until the end of the song. *Mantinádes* are much more than a means of entertainment. Many Cretans, especially the older generation, approach them as a fundamental way of expressing feelings such as love, pain, fear and loneliness and even as an *ars vivendi*, a Cretan 'art of living', which in the case of my father's illness experience was also a kind of alternative or complementary treatment.

In opening *Illness as Many Narratives* with my father's story, my aim is not simply to account for my personal interest in illness narratives (though scholarship in this area often still invites autobiographical justifications), but rather to raise a set of broader questions with which this book is also concerned: in (re)reading my father's story I knew that, as a representation, it did not offer unmediated access to his lived experience during the years of his illness. However, this does not lessen the work's expressive power; neither does the fragmentation, discontinuity or the switches to alternative genres, noted earlier, even as they draw attention to the contingent nature and inadequacy of verbal forms of communication, and the affective excess that cannot be contained by them. In gathering together the many different strands of his narrative performance, I wondered which of the stories or components in my father's account would be considered more relevant or 'fitting' for an illness narrative. Would a medical practitioner or educator skip the sections from his 'narrative of community' or try to establish connections across distinct narratives? What would critics of self-indulgent memoirs make of these vignettes that populate the narrative with the stories of the villagers, or of the *mantinádes*? How relevant is my father's national/cultural/professional background to the structure and the forms he chose for his narrative, and what kind of response do they call out in other people? What demands, if any, does his narrative make for anyone who encounters it, and how can these demands be met? What are the

ethical and other potential questions raised by my particular mode of responding to this narrative here, or my responsibility in the future (for example, if I were to fulfil my father's wish to make his story available to others)?

Responding to the criticisms that narrative has received in the last decade or so after a period of enthusiastic reception within the growing field of the medical humanities,⁴ *Illness as Many Narratives* offers ways to open up the category of illness narrative and the limited methods employed so as to produce more sophisticated and interdisciplinary readings of health, illness and medicine. It draws on important work that has been done in literary and cultural studies on the illness memoir but expands current understandings of illness narrative by adopting a comparative approach in its juxtaposition of arts/media and illnesses across and within chapters. I focus on a wide range of artistic and cultural representations – both autobiographical and collaborative projects, including mixed media forms – to create a more inclusive illness narrative canon that decentres the literary form as the paradigm for understandings of this genre and draws connections between different illness experiences. The works I discuss include photographic portraits, artists' books, performance art, theatre, film, animation and online narratives, many of which have yet to receive sustained attention, and treat breast cancer, liver disease, lung cancer, chronic fatigue syndrome and mental health. In enlarging the field's scope beyond canonical works and those bound by the context of biomedicine or merely the doctor-patient encounter, the following case studies challenge instrumental or reductive applications of the arts within the medical humanities, establish important links between medical and the broader culture and demonstrate how the arts/humanities and medicine can critically interact with each other. It is in all these ways that 'illness as many narratives' can be seen as furthering the work of the *critical* medical humanities.⁵

Illness narratives and the critical medical humanities

Illness narrative as a term is used across disciplines that inform the medical humanities, including medical sociology, anthropology and literary studies. Since Arthur Kleinman's distinction between illness and disease in the 1980s in *The Illness Narratives*, illness stories or narratives have been seen as giving expression to the subjective or lived experience of a particular disease or condition, which is distinct from the clinical definition of disease understood as an organic

dysfunction within biomedicine (1988: 3–6). The subtitle of Kleinman's book, *Suffering, Healing and the Human Condition*, emphasises the need for patients to give voice to their suffering and for medicine to find ways to 'record this most thickly human dimension of patients' and families' stories of experiencing illness' (28). Typically illness narratives combine an auto/biographical narrative about living with an illness with reflections upon the wider implications of a particular disease, treatment, recovery and interactions with medical professionals. Kleinman's *The Illness Narratives* does not discuss published accounts of illness by patients and their families, but work by Anne Hunsaker Hawkins, Arthur Frank and Thomas Couser does. In *Reconstructing Illness* Hawkins examines the emergence of what she calls 'pathographies' in the late twentieth century through their relation to the religious conversion narratives that enjoyed a parallel popularity in earlier centuries, and considers the ways underlying myths and metaphors such as rebirth, battle and the journey give form to illness narratives. In addition to writing his own illness narrative (*At the Will of the Body*), Frank has offered a typology in *The Wounded Storyteller* by describing three narrative types: the 'restitution' narrative, the 'chaos' narrative and the 'quest' narrative. While Frank as a medical sociologist is primarily interested in situating clinical ethics and social science 'within a more general ethics of the body' and moving practitioners 'in the direction of thinking with stories' (1995: 23–4), literary critics like Couser (1997) have explored autopathography as a distinctive genre that has both enriched and challenged aspects of the repertoire of life writing.

Illness narrative has grown exponentially in the mid twentieth and twenty-first centuries.⁶ Hawkins writes that 'it is surely no accident that the appearance of pathography coincides with the triumph of scientific technological medicine' (1999: xii). In *The Wounded Storyteller* Frank enlists the 'postmodern' (his study is published after Lyotard's 1984 account of the collapse of grand narratives) and the 'postcolonial' to capture rhetorically the 'writing back' to medicine that illness narratives effect (1995: 13).⁷ A series of factors and changes after the 1950s seem to have contributed to an increasing interest in representations of illness, pain and suffering by people who experience illness first-hand or those who are close to them. Framing this study as it moves (though not following a strict chronological structure) from the politicised feminist patient of the late seventies through to the increasing use of social media to communicate illness experiences in the present moment, these factors include: medical professionalisation and specialisation affecting

doctor-patient relationships; the emergence of the women's, gay rights and disability movements, as well as the powerful influence of AIDS; and of course the popularity of certain life-writing genres (self-help narratives, memoirs) and technologies that facilitated self-publication. These advances remain relevant, and have expanded considerably in the age of the rapid development of digital technology and media convergence.

Illness narratives have garnered positive attention, and their contribution to narrative medicine has linked them with the notion of 'narrative competence' (Charon 2006: 12), turning them into tools that enhance clinical diagnosis and treatment and provide valuable insights to medical practitioners as well as patients. Despite this recognition, in 'The Limits of Narrative' medical humanities critic Angela Woods highlights a series of pressing questions about the use of narrative in an effort to reignite debate about its role in the field. The valorisation of narrative as 'the mode of human self-expression' (2011a: 74) promotes ideas of individual authenticity and a particular kind of self (neo/liberal, Western, middle class). These ideas have been equally questioned by social scientists who seek to locate illness narratives in a wider social context,⁸ and by literary/cultural studies scholars who approach them as 'texts' or draw attention to a range of narratives (cross-cultural, queer) that challenge normative assumptions. Woods, however, more fundamentally highlights 'the normativity of narrativity' (76), in other words the suggestion that conceiving one's life as a narrative or story is fundamentally healthy, desirable and necessary. This is an assumption that characterises Frank's typology whereby the quest narrative is presented as an ideal to which everyone should aspire in order to reclaim and reorient the self that has been disrupted by illness:

Restitution stories attempt to outdistance mortality by rendering illness transitory. Chaos stories are sucked into the undertow of illness and the disasters that attend it. Quest stories meet suffering head on; they accept illness and seek to *use* it. Illness is the occasion of a journey that becomes a quest. (1995: 115)⁹

Woods writes that 'narrative returns us again and again to structure, coherence and unity ... What place is there for formlessness, for meaninglessness, for silence?' (2013: 125). Rather than arguing that we should 'discourage patients and doctors from telling stories or view with suspicion anyone whose sense of self is articulated in narrative terms', she suggests that scholars in the medical humanities

can do more 'to foster a critical approach to the normative scripts of particular kinds of narrative', as well as 'more radically' move beyond narrative (2011a: 76).¹⁰ The latter is framed as 'an invitation' that Woods believes 'scholars and practitioners in the medical humanities must be ready to accept' (2013: 126).

Woods' reminder of the limits of narrative is an important intervention in the field, but there is more to say about this term and the ongoing potential of illness narratives to shape wider debates about health, illness and the medical humanities. This is why the title of this book retains the term 'narrative' even as it defamiliarises it by linking it to different media and artistic forms. The proliferation of illness representations in contemporary culture attests to continuing forms of silencing at the hands of biomedicine while also informing a wide range of artistic and cultural practices. (Auto)pathographies and illness memoirs are well represented in illness narrative scholarship, but this is not the case for other media and artistic forms that intersect with narrative. Moreover, stories of particular conditions, and especially of mental distress, are comparatively fewer, and medical humanities is 'culturally limited by a pedagogical and scholarly emphasis on Western cultural artefacts' (Hooker and Noonan 2011: 79). This series of qualifiers, taken up in the following chapters, begs the question whether moving beyond narrative would be necessary or desired if we were to define narrativity more broadly¹¹ and multiply existing narratives. Even though some critics are adamant that this should be 'only a first step' (Sartwell 2000: 84), I would argue that there is room to challenge *and* expand narrative's conception and role within the medical humanities field, and that the works I consider in this book invite us precisely to do both.

There has been a tendency in the 'first wave of medical humanities', since its establishment as an identifiable field in the early 1970s (first in the US and later in the UK) and the rise of pathography in the 1980s and 1990s, to treat narrative as synonymous with verbal, if not literary, expression and to define it in terms of linearity and coherence. However, as scholars in literary studies and across disciplines have shown, illness stories often challenge chronological causality and unity. Cheryl Mattingly coins the term 'emergent narratives' to describe those stories (in her case within the clinical encounter) that, though still dependent on existing cultural resources, are 'embodied' and 'improvised' rather than told. Emergent narratives are 'clearly allied to performative views of narrative and action' and are not characterised by coherence but rather 'narrative drama'. Mattingly's description of 'how we follow a narrative suspensefully, always reminded of the fragility of events, for

things might have turned out differently' (2000: 205) resonates with my discussion of film and performance in Chapters 4 and 5. Illness narratives take many forms and embrace different genres and media, some of which intersect with narrative as it is conventionally understood. In fact, two of Woods' proposed alternatives to narrative discussed in 'The Limits of Narrative' – metaphor and photography – function in this way, rather than as strictly anti-narrative modes. Woods herself acknowledges this when she describes metaphors as 'building blocks of narrative' that drive the story forward even as they lack the larger temporal structure of narrative (2011a: 76). Similarly, the myth of the photograph as a purely visual image has been challenged. Photographs often have captions and titles, if not a longer text attached to them; and as Victor Burgin and others have suggested, even when this is not the case, they are 'traversed by language' when they are interpreted by viewers (1982: 144).¹²

When approached as a communicative act and as essential to the process of meaning-making, narrative is not tied to a single medium. Alongside photography and forms that gesture towards narrative without appealing to elaborate stories (for example, the short animated film that has affinities with metaphor), this book focuses on works which, even though they do not rely exclusively on linguistic expression to give shape to experiences of physical and emotional distress, do not abandon it altogether. In this way, I show how the category of illness narrative can be opened up by addressing some of its limits and conservative assumptions from within, that is, through the works' own generic multiplicity and mixed-media nature that often lead to important aesthetic collisions. Thus word and image in photography; stories and images or distinct visual modalities in documentary film; text and the various other elements of an artist's book; performance art and theatrical conventions in autobiographical theatre; and animated drawing and documentary voice in animated documentary collide, but also enrich each other, in the following case studies. While acknowledging that the term illness narrative can be trivialised through overuse and overinflated, as Woods cautions, I believe that expanding rather than limiting current definitions and approaches to illness narrative can benefit medicine, the arts and cultural studies.¹³ As the medical humanities is moving towards a new phase, taking stock of the need to forge alliances with the arts and humanities in order to remain pluralistic and experimental, it is a timely moment to recognise the many narratives of illness in all the senses of this phrase: the multiplicity of illnesses and their treatments; the different arts and media that need to be included in the

field; and finally, the range of methods that will foster a more critical engagement with health, medicine and culture.

Many directions have been indicated in the last few years with the goal of enlarging the scope of the medical humanities and sharpening its critical edge. The medical humanities, we might say, suffers from an identity crisis, and nearly every conference or publication in the field includes a discussion of defining or redefining its name, boundaries and approaches. In its response to Howard Brody's three personalities of the medical humanities ('disciplinary list', 'programme of moral development' and 'supportive friend'),¹⁴ the Centre for Medical Humanities at Durham University (2011) in the UK has recently suggested that 'those purposes are very much anchored within the culture and practices of medicine and are engaged in serving it'. The problem with conceptualising the field in an "instrumental way" is that we prevent it from gaining sufficient distance from medicine to take a radically critical view'.¹⁵ Woods, Anne Whitehead and Alan Bleakley, writing from different disciplines but intersecting in their interest in medical humanities, emphasise the need for a more critical medical humanities. Bleakley favours critique and resistance, a more interdisciplinary approach that avoids 'Western imperialistic tendencies' and a less 'utilitarian and artistically conservative model' (2014a: 23–4). Whitehead also takes issue with the dominant conceptualisation of the medical humanities in 'purely humanising or humanistic terms' (2014: 119). She proposes a shift from practitioner pedagogy and training (or an 'additive' view) towards a more 'integrated' view whereby the nature, goals and knowledge base of clinical medicine might be 'challenged and reshaped' rather than simply 'softened' by its encounter with the humanities (108). While in the following chapters I suggest that the value of the medical humanities is not limited to educational concerns, I am keen not to dismiss the distinct pedagogical potential of the artistic forms I consider – particularly the ways a more critical or radical pedagogy emerging from different sites and media can reshape and challenge existing practices within medical education.¹⁶

The discussion about the limits of narrative, like the debate about the goals and purposes of the medical humanities, has perhaps been divisive, but it does not have to be approached in purely negative terms. As a terrain where vital issues are being negotiated it has also served as a necessary precondition for renewed transformative articulations in the field, and thus as a form of giving new energy and impetus for conversation. This more positive view, which this book embraces, is evident in Keir Waddington and Martin Willis' journal special issue 'Rethinking Approaches to Illness Narratives'. They

argue that ‘the limited range of methods presently employed unnecessarily restricts what illness narratives might be allowed to mean, and even what they might look like’ (2013: iv). Contributors to this special issue make a plea for ‘reclaim[ing] the aesthetic and imaginative qualities from a system that reduces illness narratives (and healthcare more broadly) to nothing more than a further set of utterances that provide specialist medical data’ (Willis et al. 2013: 68). Such utilitarian sensibility is something that often characterises approaches coming from the social sciences, where, typically, illness narratives are viewed as data to be solicited through interviews and then transcribed and analysed through certain methodologies. Even when this is not the case, the selection and analysis of illness narratives are normally framed by the doctor-patient encounter rather than other actors, and by the context of biomedicine, instead of situating their contribution in various aesthetic, historical and political traditions. Like these critics, Susan Merrill Squier argues in favour of the introduction of a more diverse set of literary texts and a new set of reading practices that ‘can release us from the contract to which we are bound when we accept the implicit frame of both medicine and literature’. She envisages a more inclusive canon that would encompass not only canonical fiction and poetry, but also ‘the full range of written cultural expression’ (2007: 338). Whitehead similarly endorses the potential of the field ‘to engage with an expanded notion of literary genre’, including more experimental and ‘mixed-media narrative modes’ that redress the dominance of realist fiction and autobiography in existing scholarship (2014: 114).

In many ways such calls for more nuanced and sophisticated approaches to illness narratives are beginning to be addressed in the work of scholars trained in literary and cultural studies, including the aforementioned critics. Susanna Egan, for example, has explored the challenges disability and illness pose to autobiography and life writing more broadly, leading to generic experimentation, ‘instability in perspective, narration, medium or authority’ (1999: 28). Such approaches deconstruct the idea that illness narratives are linear or offer coherence, place narratives in historical and cultural contexts as opposed to following typologies, and intervene in more traditional approaches to literature such as Rita Charon’s, which privileges a specific canon and approach to texts (realist fiction and autobiography, and close reading indebted to New Criticism). However, their contribution has not been recognised in mainstream medical humanities criticism, which still revolves around the influential models of Brody, Couser, Frank, Hawkins and Charon.